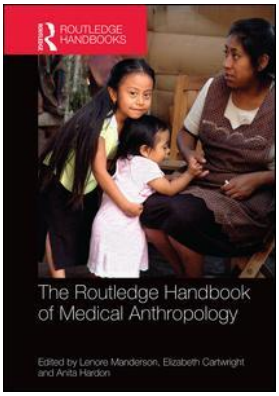

The Routledge Handbook of Medical Anthropology

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Genes, Kinship and Risk

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Anthropometry in the Guatemalan Highlands, 2014. Sololá, Guatemala.

About the photograph

Medical anthropologist Caitlin Baird measures the growth of children at an NGO-sponsored preschool in the Guatemalan highlands. Baird works with Wuqu' Kawoq: Maya Health Alliance, as part of a team of anthropologists, physicians, nutritionists and NGO workers who are studying child growth in rural areas of Guatemala.

Guatemala has the highest rate of chronic malnutrition in the Western Hemisphere, and one of the highest rates in the world. Chronic undernutrition in early childhood, a condition commonly referred to as 'stunting,' causes permanent delays in cognition and in the development of multiple organ systems, leading to both a loss of productivity in adulthood and a hugely increased disease burden. The combined burdens of greatly increased incidences of chronic disease and lower economic productivity as adults are mutually reinforcing and act as a drain on already at-risk households, re-establishing the cycle of poverty (and undernutrition) in subsequent generations.

—Caitlin Baird and Amber Urquhart

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Genes, Kinship and Risk

Anita Hardon, Lenore Manderson and Elizabeth Cartwright

In her fascinating book *The Century of the Gene*, sociologist Evelyn Fox Keller (2001) argues that we need to understand the multiple histories and understanding of the word 'gene' to make sense of contemporary 'gene talk.' More than a century after the word 'gene' was coined, biologists still do not agree on what a gene is nor what it does. Keller describes how the term 'genetics' emerged in the early twentieth century, when Hugo de Vries, a Dutch botanist, and his contemporaries rediscovered the rules of inheritance that Gregor Mendel, a solitary Austrian monk, had found 40 years earlier in his investigations of pea plants (Keller 2003). A new and well-developed branch of plant breeding emerged with a focus on the material basis of inheritance patterns; in this context, the English scientist William Bateson (1906), speaking to a congress of botanists, coined the term 'genetics.' The term 'gene' was introduced three years later by the Danish plant physiologist Wilhelm Johannsen, who wanted a new word to replace earlier concepts such as 'genmules,' the Darwinist unit of pangenesis, and de Vries's term 'pangens.' Johannsen argued "it appears simplest to isolate the last syllable, 'gene,' which alone is of interest to us" (1909: 124).

These developments occurred long before James D. Watson and Francis Crick unraveled the structure of DNA in the 1950s (Olby 1974), after which genes became defined as segments of DNA that carry coded information, and geneticists began to study hereditary conditions and traits regulated by specific DNA sequences. The late twentieth century was a period of optimism for geneticists, who, through international collaborations and generous public and private funding, set out to map the human genome. At the time, scientists expected that the genetic information uncovered through such large-scale mapping exercises would result in new knowledge of the regulation of bodily processes, which could be instrumental in diagnostics and therapeutics. Knowing which nucleotide sequences produce which proteins would enable genetic engineering to shape the biological basis of life. A rapidly expanding biotechnology industry invested in medical genomics, with increasingly strong ties between geneticists and commerce, all promising a better future in which both disease prevention and treatment could be personalized. Celera Genomics, a private company, aimed to speed up the mapping of the genome in order to gain intellectual property protection for the genes that it identified. By 2000, Celera Genomics had applied for thousands of patents on the genes it had discovered (Happe 2013).

The potential patenting of human life led to much concern among scientists and the public in the United States and Europe. On March 14, 2000, at the US National Medals of Science and Technology award ceremony, President Bill Clinton announced a joint agreement

between the United States and the United Kingdom to lead the way in opening access to genomic research, declaring that the raw data generated from the human genome project should be accessible to all. Clinton stated, "we must ensure the profits of human genome research are measured not in dollars but in the betterment of human life" (Venter 2007: 299). The US Patent and Trademark Office decided that 'raw data' on the sequence of human genes could not be patented.

Genetic Testing

These developments followed the growing use of genetic testing, beginning in the 1980s in antenatal care, to identify abnormalities in the fetus, as described in Rayna Rapp's ethnography entitled *Testing Women, Testing the Fetus* (2000). The range of conditions for which the fetus could be tested was limited, however, and testing in pregnancy was generally accompanied by genetic counseling that provided the pregnant woman or couple with some basic understanding of the test results. As described in the first case study in this chapter, in some places companies only provide results of genetic testing in writing, and clients are left to decide for themselves how to make sense of them. Without accompanying information, these tests may be given more weight than they should, and even with counseling, the meaning of any risks may be poorly understood. Being tested can lead to worries about future health, including unnecessary investments in all kinds of preventive procedures and products, as we discuss below.

A major breakthrough in understanding the relationship between heritability, risk, and genomic medicine was the identification of the BRCA (breast cancer) gene sequence; the gene is used to identify women with a high BRCA-related susceptibility for getting breast and/or ovarian cancer. To prevent these cancers, women who have this gene may be advised to have their breasts and ovaries removed. Since testing for BRCA has become common, many women, including actor Angelina Jolie, have shared their experiences through social media and news reports. Women diagnosed with BRCA are also advised to tell female family members about the diagnosis, and they in turn need to decide whether they want to be tested, and what to do if they test positive. BRCA diagnostic tests can have significant consequences for women and their families, including, when ovaries are removed, surgical menopause. Even so, the general public does not seem to see testing for the BRCA gene and subsequent preventive medical interventions as an extreme measure. Rather, breast cancer advocacy programs and women who have been tested for the gene argue that the BRCA test empowers women to make lifesaving decisions. Social studies of science and technology have described how women with the BRCA gene mobilize through the Internet and breast cancer support groups based on this shared genetic disposition (Klawiter 2008).

As the Human Genome Project identified more and more genes, it became clear that the association between gene sequences and the incidence of disease is not as straightforward as first thought. While a connection has been made between breast cancer and BRCA, further epidemiological research has shown that the genetic mutation in BRCA1 or BRCA2 accounts for only a small proportion of all breast and ovarian cancers, and not all women with the genetic mutation will develop either disease or both diseases. Men with BRCA gene mutations are also at higher risk of breast cancer, as well as prostate cancer, but preventive surgery has not been proposed as an option for men. Thus, genetic researchers increasingly point to the complex interactions between genetic makeup, biological processes, 'lifestyle' (or personal habits), and the environment that determine the expression of genes.

Given this complexity, how should people make sense of positive test results, especially when geneticists can only give rather rough predictions about the chances of becoming ill? Margaret

Lock (2013) conducted a study on the biological understandings of one such ambiguous condition, late-onset Alzheimer's disease (AD), which genomic researchers associate with the so-called APOE gene. This gene comes in four forms, but only one of them, the APOEε4 allele, has been found to put people at risk for AD. In her extensive review of the biological studies, Lock points out that getting AD is not necessarily related to a positive test for the APOEε4 allele. At least 50 percent of people with this gene do not get AD, and 30 to 60 percent of people with AD do not have the gene. Meanwhile, more and more genes are being identified as having a positive association with AD. Lock's work reveals that biological insights into late-onset AD are subject to continual revision, and are still far from conclusive. As a consequence, Lock suggests that learning about one's APOE status "does not provide information about a highly probable future: it only raises a possible scenario, that everyone living in a family where AD is present has already entertained at some point in their life" (2013: 63).

Lock's research is illustrative of a growing number of social science studies that have followed the developments in the mapping of the human genome and medical genomics with some skepticism. Paul Rabinow (1996), writing about biosociality, and Nikolas Rose and Carlos Novas (2005), offering the idea of biological citizenship, have both anticipated that increasingly social life would be structured around our genetic identities. Lock (2013) has countered that when the relation between genes and illness conditions is ambiguous, genetic makeup fails to be a basis of our identity. Social scientists have also emphasized that disease is not only a biological condition located in the body, but also the outcome of socioeconomic and environmental conditions. In some cases, genetic testing may resolve for an individual the uncertainty around whether or not he or she will develop a disease, and so enable the person to plan for this possibility, as Flaherty and colleagues (2014) have illustrated for people with family histories of Huntington's disease. But others warn that genomic medicine could decrease the quality of life for people who interpret risk as disease, and who thought they were healthy until they received the positive results of a genetic test. Uncertainty remains, however, even with positive test results: a person may or may not develop a particular disease, and if they do, there may be no treatment for it.

In the first case study in this chapter, Suli Sui and Margaret Sleeboom-Faulkner discuss how genetic testing is promoted in China, with promises to clients that such tests 'decode the mystery of life' and 'predict future health,' even if the results of the tests have limited predictive value about future health and wellbeing. Sui and Sleeboom-Faulkner describe how private genetic testing companies send clients reports on their predisposition to get a large number of diseases as 'high,' 'medium,' or 'low' as compared to 'average' individuals without a given gene. If, for example, the results identify a medium-level risk of developing Alzheimer's disease, the reports indicate that the client's probability of getting the disease is five times higher than a person without the gene. The companies usually offer lifestyle advice, including the use of vitamins and minerals. Thus, the tests work to medicalize people's lives: not only are they defined as "presymptomatically ill" (Rose and Novas 2005: 445), but also they are expected to buy preventive nutritional supplements to avoid becoming ill.

Besides testing for susceptibility to disease, Sui and Sleeboom-Faulkner reveal that some companies offer genetic tests personality traits such as optimism and shyness, the likelihood of becoming addicted, and intelligence. The prices of such tests are quite high for ordinary people, varying from 400 RMB to 10,000 RMB (approximately US$650–1,600). Still clients seem interested in having the tests done. In a country with a one-child policy, parents want to find out what their child is worth. Sui and Sleeboom-Faulkner suggest that being diagnosed with a particular gene not only determines one's own sociality, but also parents' investment in their children's future.

14.1 Direct-to-Consumer Genetic Testing in China

Suli Sui and Margaret Sleeboom-Faulkner

Commercial genetic testing (CGT) is usually promoted among individuals with an increased genetic susceptibility conferring a predisposition to future disease symptoms (Fulda and Lyken 2006). In China, the application of predictive genetic testing and its commercialization are becoming increasingly popular. Many biotech companies offer genetic testing to customers, including individuals or organizations. Customers buy tests direct from the company through company agents or online. The scope of testing services is widening, and the modes of business operation are becoming simpler, with some companies solely selling tests online, as is the case with Genetic Testing Net and Zhong-Ren Gene-Net.[1]

In February 2014, the Ministry of Health (MOH)[2] and the China Food and Drug Administration (CFDA) jointly issued the *Notice on Strengthening the Management of the Clinical Use of Gene Sequencing Products and Technology*. This notice points out that gene-sequencing products and technologies, including prenatal genetic testing, belong to the field of advanced product and technology research. They involve issues of ethics, privacy, protection of human genetic resources, and biological safety, and issues related to technology management, price, and quality control of the medical institutions that offer genetic testing services. The purpose of this notice is to guarantee the safety and efficacy of genetic products, and to strengthen the supervision of clinical applications of new genetic technologies. The notice has officially stopped all clinical application of genetic testing in medical institutions until new licensing criteria and relevant regulation are enacted. However, the management and operation of genetic testing offered by companies is outside the supervisory radar of the MOH or the CFDA, so that companies are continuing to offer genetic tests for clinical purposes (Sui and Sleeboom-Faulkner 2007).

As with other commercial companies in China, biotech companies planning to set up a genetic testing business need only to apply for a business license from the local Industrial and Commercial Bureau. They are neither limited in how they market their testing products, nor do they need any special medical qualifications or permissions from the MOH and the Ministry of Science and Technology; the staff of these companies do not need any medical qualifications. CGT in China was incentivized by the availability of genetic testing technologies and a large pool of potential customers. Currently, the testing price varies from 4,000 to 10,000 RMB (US$650–1,600; in November 2014, the exchange rate was 1,000 RMB = US$164) depending on the number of testing items.

Some biotech companies declare on their websites that they collaborate with a state university or research institution, even when only one or two technical advisers are employed there. Such declarations aim to obtain the trust of the public, as people are presumed to trust state educational institutions more than commercial enterprises. In the advertisements, the companies offer genetic testing services for a wide range of multifactorial diseases. For example, Chongqing Xiehe Gene Center declares that it offers genetic tests for the genetic predisposition to 110 diseases. One principal staff said that technically their genetic testing could test for more than 1,000 diseases, but most of them were rare. Thus, considering low detection efficiency and high testing cost, 110 tests (related to the three main kinds of human diseases—cardiovascular diseases, cellular immunity, and cancer) were finally selected for their testing services portfolio. A test requires one or several drops of blood or a few mucous membrane cells from the client to test whether he or she is a carrier of genes associated with certain diseases, so to determine his or her predisposition status.

To gain market share, some biotech companies have agents in more than one large city. The first author visited one biotech company in Shanghai with an office and special agent in Beijing. This company offers 'door-to-door' services (other online companies do not involve any intermediary agent). After payment, the company sends sample equipment to clients by express mail for the collection and return of oral mucosa. After the tests are analyzed, the client receives the report of her or his predisposition status. Usually, the results are stratified into three categories of risk—'high,' 'medium,' and 'low'—but no exact percentage is attached to these. The probability of contracting a disease is explained in terms of likelihood in comparison with the 'average' individual without such a predisposition. If, for instance, the results identify a medium-level risk of developing Alzheimer's disease, the explanation is that the client has a five-times increased probability of developing the disease compared to an average person. The report usually provides advice on a healthy diet and lifestyle, allegedly to prevent and avoid the disease in question.

In promotion, biotech companies use attractive and striking phrases, such as "decode the mystery of life, predict your future health," "genetic testing—the most fashionable healthy lifestyle in the

twenty-first century," "personal treatment, decode health," and "create a healthy life based on genetic technology." These sensationalist advertisements aim to convince potential customers that genetic testing can provide predictable health and a healthy future. Some companies claim that genetic tests are suitable for anyone, and encourage healthy people to purchase tests for themselves, their partner, their children, and their parents. They also encourage employers to purchase tests for their employees. To deal with commercial competition, some companies offer sets of services at discount prices, exemplified by the test price of Chongqing Xiehe Genomics Center being 3,995 RMB for 33 diseases, 6,995 RMB for 60 diseases, and 9,995 RMB for 110 diseases.

Besides the genetic testing for susceptibility genes, some companies, such as Chongqing Xiehe Genomics Center, Zhong-Ren Gene-Net (Beijing), and Henan Yujing Bio-Technology Company, offer genetic tests for "talent genes," "rational drug use," and "safe drug use." These kinds of tests mainly target children, usually between 4 and 13 years of age, a huge group of potential customers in China. Talent genes divide into several major items, including personality, emotion, art, sport, and IQ, and 40 to 50 sub-items including genes for optimism, shyness, passion, depression, puppy love, and alcohol addiction. The various gene items all include numerous potential abilities and imperfections. The price of testing for one talent gene item is approximately 600 RMB, and 4,000 RMB for a set. Additionally, some companies sell a test for the "beauty gene," targeting women longing for beauty, a large group of consumers. For example, Henan Yujing Company sells genetic tests for "skin color," "no wrinkles," "antioxidation," and "cell renewal." It declares that such tests can assess the most suitable nutrients and beauty determinants for skin.

Reliability of Test Results and Advice

The results of commercial genetic tests, as noted, are usually expressed in terms of high, medium, and low susceptibility, partly because commercial genetic testing is not formally regulated, and because there is still no universal standard for describing genetic risk. Companies claim that the criteria used in test reports draw on state-of-the-art scientific papers in the fields of medicine, genetics, biology, and epidemiology. Until today, regulatory bodies have not decided which institutions should have the authority to approve and control such criteria. Several biotech companies ask their clients to answer a questionnaire about their everyday life. Shanghai Rongjian Bio-Technologies Co., Ltd tell their clients that precision and honest responses will help the company confirm the relationship between the client's genetic heredity and his or her lifestyle. The company also asks for reports from recent health check-ups to help the company provide health advice. To some extent, then, the clients themselves provide the testing results for the report.

Usually, the reports contain a section on the actual predictive result of the test and a section on prophylactic measures, aimed to enhance the significance of the outcome. The advice usually concerns lifestyle, diet, and intake of vitamins and minerals. For example, the Beijing Huada Gene Research Center gives the following advice to prevent senile dementia in a sample report of the genetic test results: "Take physical exercise for half an hour each day; do mental exercises at least for two hours a day, by for instance playing chess, playing cards and reading; do not smoke; eat five pieces of fresh fruit and vegetables every day; drink eight cups of water a day; and, take enough rest and sleep."[3] Although this advice may be sound, one need not take a genetic test to obtain such knowledge. In fact, the positive result of a test may have a negative effect on the behavior of the person concerned. For instance, Mr Chen, a Beijing citizen in his 40s, now feels free to smoke more after taking a predictive test that did not detect any gene that predisposes him to developing lung cancer.

Doubts arise about the existences of such items as the so-called talent gene, and whether they can be standardized for genetic testing and diagnosis. Without reliable proof of the existence of such genes, the genetic tests for 'talents' may misinform education choices for the children with or without a certain talent gene. In some cities the genetic test for talent has become popular. In 2009, the city of Chongqing carried out a 'talented baby project,' using advanced genetic testing to select 50 children with special talents, and helped cultivate them according to their talent gene. Given the reliability of these tests, an emphasis on the talent gene might create the impression that inborn intelligence is more important than postnatal education and diligence. This may unduly influence a child's motivation and the parents' willingness to invest in his or her future. Furthermore, parents' high expectation of their children might lead to disappointment, and undermine the relationship between parents and children.

No Genetic Counseling Available

According to Article 11 of the UNESCO *International Declaration of Human Genetic Data*, it is an ethical imperative that where genetic testing has likely significant implications for a person's health, appropriate genetic counseling should be made available. Genetic counseling should be non-directive, culturally adapted, and consistent with the interests of the person (UNESCO 2003). However, questions arise as to who is the appropriate expert to counsel the patient and/or the family, and how to counsel them (Fulda and Lyken 2006).

While companies claim to offer counseling, in practice this involves a promotional session used to introduce the price of the genetic test, the test procedure, and the benefits of the tests on offer. No professional genetic counseling is provided. The perceived risk of developing a hereditary disease, especially those for which there are no cures or for those that are severe, is usually accompanied by considerable psychological distress (Friedrich 2002). As environmental factors complicate the interpretation of genetic test results, even with well-trained genetic counselors this is difficult. In China, without appropriate support from professional genetic counselors, test results that are unreliable, and important genetic abnormalities that remain undetected, no responsible provisions can be made for the potential patient (Sui 2009).

Genetic Information and Privacy

Genetic information is different from other personal information because it concerns the privacy of family members who usually share the same or similar genetic information (O'Neill 2002). The confidentiality of genetic information is regarded as highly important both for individuals who undertake tests and those who may be affected by the test results. The failure to protect privacy and confidentiality could lead to genetic discrimination. Biotech companies with access to genetic information on their clients and their families have the duty not to reveal the data to third parties. This is crucial as such information is of potential interest to employers, insurance companies, and even governmental agencies. Especially genetic information of children or other vulnerable persons should be carefully protected, as they are dependent, and not fully competent or able to make free and informed decisions. For example, the sale of predictive genetic tests for talent or potential might harm these children. If such a child is branded for carrying, say, a gene for being 'prone to violence' or 'prone to depression,' it may have a deep psychological impact on the child, and could result in social stigma and genetic discrimination. Similarly, if a child is regarded as a 'genius' on the basis of a genetic test, the high expectations of parents and society regarding gifted children might also put a heavy burden on the child.

Personal Autonomy and Free Decision Making

Personal autonomy is regarded as a basic ethical principle, and refers to the individual's capacity for self-determination. People have a right to make their own decision to undergo a test, independent from the views of others. The situation in which parents buy genetic tests for their child is more complex. If a child's adverse test results are received at a very early age, the child may have to live for a long period with the prospect of a later onset of the disease in question, and parents will fail to achieve their original well-meaning intention. The child, in turn, might regret knowing about the diagnosis, the consequences of which might continually worry them. To some, not knowing may mean a less worrisome life.

The decision to take a talent gene test is made by the parents, who usually ignore the personal feelings of their children about the matter. Parents in China are especially concerned with the education of their children, and are willing to invest heavily in this (Kipnis 2011). The association between talent, education, and the future of the family household is important, leading to decisions in which the children themselves sometimes have little say. In fact, a similar situation exists when adult children buy tests for parents or when a spouse buys a test for his or her partner. For example, one company offers a special set of tests for elderly people, named 'filial piety.' It encourages people to buy their set of tests as a gift to express their filial piety to their parents. These issues, concerning personal autonomy and free decision making, should be taken into account and should be part of any attempt to regulate commercial genetic testing and enhance its supervision.

Conclusion

In China, genetic tests by biotech companies are increasingly available. Partly due to the lack of regulation and supervision of commercial genetic testing, socioeconomic and ethical governance issues have emerged. The issues brought about by the application of commercial genetic testing, including the effects of misleading advertising practices, the suitability of the groups targeted for potential customers, the reliability of test results, and the unavailability of genetic counseling for clients, deserve more attention from the public and the authorities.

Notes

1. The website of Genetic Testing Net is: www.jiyinjiancewang.org. The website of Zhong Ren Gene Net is: http://yiyaowang.org/index.html.
2. On March 17, 2013, the Ministry of Health had changed its name to National Health and Family Planning Commission. For better understanding, this case study still uses MOH.
3. The template concerned is downloaded from: http://south.genomics.org.cn/genetest/template.doc.

References

Friedrich, M.J. 2002 Preserving privacy, preventing disclosure becomes the province of genetic experts. *Journal of the American Medical Association* 21:815–821.

Fulda, L.G., and K. Lyken 2006 Ethical issues in predictive genetic testing: A public health perspective. *Journal of Medical Ethics* 32:143–147.

Kipnis, A.B. 2011 *Governing Educational Desire: Culture, Politics, and Schooling in China.* Chicago, IL and London: Chicago University Press.

O'Neill, O. 2002 *Autonomy and Trust in Bioethics.* Cambridge, UK: Cambridge University Press.

Sui, S. 2009 The practice of genetic counselling—A comparative approach to understand genetic counselling in China. *BioSocieties* 4:391–405.

Sui, S., and M. Sleeboom-Faulkner 2007 Commercial genetic testing in mainland China: Social, financial and ethical issues. *Journal of Bioethical Inquiry* 4(3):229–237.

UNESCO 2003 International Declaration on Human Genetic Data. Article 11. Adopted unanimously and by acclamation on 16 October 2003 by the 32nd session of the General Conference of UNESCO.

The marketing of and consumer desire for testing such a broad range of genetic traits is a new development in China, as is the case elsewhere in the world. Biotech companies increasingly see a profitable market for these tests, even if they cannot offer much in terms of prevention or cure. However, as Sui and Sleeboom-Faulkner point out, questions arise about the reliability of such tests. Tests can have false-positive and false-negative results, and gene–environment interactions and lifestyles also determine both the expression of a gene and life outcomes regardless of genetic profile.

Kinship and Genes

Kelly Happe (2013) argues that the recent advances in genomics have contributed to a discourse in which disease is evidence of inherited defects, rather than embodied life. It is, she argues, a political worldview that ignores the embedding of bodies in historically specific environments, in particular socioeconomic circumstances. The fact that exposure to toxins and living in polluted environments can cause cancer is increasingly ignored. Pollution is seen to be an inevitable characteristic of modern life and cannot be avoided. Rather than toxins, "inherited genetic mutations are the polluting agents, a conceptual displacement that is part and parcel of a neoliberal logic that valorizes personalized, market-driven medical and public health interventions" (Happe 2013: 139).

Genetic testing anticipates the likelihood of the development of a particular inheritable condition, as we have noted, but while genetic work-ups may illuminate the risk of disease for a particular

patient, tests provide little hope for its treatment and cure. However, biomedical research continues to explore the potential for treatment, and so sustains hope among families affected by congenital disease for the future treatment and cure of conditions that are presently fatal. People with family histories of incurable inherited conditions are especially attracted to the promise of future medical discovery and success, and in this context various biomedical companies build on medical knowledge for profit. Hence the lure of banking genetic material on the basis of the promise, or possibility, that discoveries downstream will provide desirable treatments and cures. In the following case study from Simonetta Cengarle, we see how human umbilical cord blood has been commodified, with commercial banks employing notions of potential risks for and anticipated cure of disease for the baby, its siblings, and even its parents. According to the American Academy of Pediatrics (AAP), an infant's cord blood should not be banked for future use by that infant because:

> Most conditions that might be helped by cord blood stem cells already exist in the infant's cord blood (i.e., premalignant changes in stem cells). Physicians should be aware of the unsubstantiated claims of private cord blood banks made to future parents that promise to insure infants or family members against serious illnesses in the future by use of the stem cells contained in cord blood. Although not standard of care, directed cord blood banking should be encouraged when there is knowledge of a full sibling in the family with a medical condition (malignant or genetic) that could potentially benefit from cord blood transplantation.
>
> *(American Academy of Pediatrics Section on Hematology/Oncology et al. 2007: 167)*

The AAP goes on to encourage the donation of cord stem cells to accredited national cord blood banks, but it cautions that private storage of umbilical cord stem cells should not be viewed as health insurance. Given the extremely high prices of cord blood banking, and the ways in which parents' fears are manipulated through vague claims of efficacy or the promises that medical science might deliver in the longer term (Petrini 2014), the following case study makes an important contribution to our knowledge about how this practice has been taken up in Southeast Asia and elsewhere.

14.2 Harvesting Umbilical Cord Blood

Simonetta Cengarle

Parents attending private antenatal medical clinics are often surrounded by information on umbilical cord blood banking. In a brochure, THAI StemLife, an umbilical cord blood bank, warns parents to "Protect your family's future by preserving its origins!" The text continues, "one thing we cannot do is to predict what will happen to our loved ones in the future. Unfortunately, accidents or disease can strike down even the fittest of us. But now doctors have a new weapon in the ongoing fight against disease in the form of stem cells: microscopic miracles, which are found in each and every one of us." The company's video on YouTube (in Thai) takes the viewer through a similar message (https://www.youtube.com/watch?v=EWIZanUvf04&feature=youtube) ending with the tagline, "Stem Cells for a Safer Feature." On its website, mention is made that "medical advances now allow you to choose a 'true life insurance' which can be used to save or prolong the life of the policyholder. This true life insurance enables individuals to store their own stem cells for their own future health needs" (http://www.thaistemlife.co.th/content/?p=104&c=54).

The language used in the sales pitch and marketing materials of umbilical cord blood banks makes it difficult for parents to ignore. It characterizes a notion of good parenting and strikes at the

deepest fear of every parent: something may happen to their child. Cord blood banks are essentially assurance of the future health of a child. In their marketing, these biobanks use ideas and language affiliated with the private banking sector and investment companies. Clients are seen as investors who need to accumulate some security for the future. As one of my research participants, Esther, noted, "if something happens, I mean to these girls, they get a disease or whatever, and it might help and I would really regret that I haven't done it."

Since the first successful transplant in 1988, in which stem cells from a sibling were used as an alternative to bone marrow to treat Fanconi's anemia, umbilical cord blood banks have sprung up everywhere (Gunning 2004). Now banking storage facility companies are growing and expanding in all parts of the world. Asia is particularly prolific. Although in this case study I draw on research I conducted in Thailand and Singapore, the business of biobanking is global. Many parents are interested in covering their children's future by buying insurance that may save their lives. What most parents are not told, and may not understand clearly, is that private banks count on future technology to reap the benefits of umbilical cord blood cells rather than being grounded in technology currently in use. Although many conditions now can be treated with stem cells, there is an expectation too that future medical breakthroughs will provide the necessary medical fix for others (Brown and Kraft 2006: 314). At the moment, the amount of cells collected would be enough only to treat a child and not an adult, but in marketing their services, the banks use vague language to assure potential clients that the technology to grow cells in culture will soon be available. Also, the cord blood is rarely used for autologous transplant; more often it is used for siblings.

Stem cell research is dynamic and fast moving. Whilst results have not been transferred so rapidly as to change people's lives, commercial companies have been quick at attracting an ever-expanding audience which lives in hope and fear: fear of what the future may hold in terms of diseases and hope in a new technology that, will, one day, miraculously cure all chronic and deadly diseases. In the span of just a couple of years, private stem cell banking companies have gone from offering only umbilical cord blood storage facilities to banking almost every possible source of stem cells. As Siew Lian commented, "It's like, you buy it not knowing whether you will use it or not. So to me I feel like, if you look at this point of view, it's more like an insurance. You may use it, you may not use it. At the end of the day your money for the 21 years may just go down to waste but at the end of the day you could still use it . . . Of course we hope that our money will just go to waste and we will never use it again at all. So to me I feel like that is why it is like an insurance, you do not know whether you will need it." Her husband David added, "Ultimately it's just an insurance for the kid. Our parents, none of our parents did it before, it's just that nowadays a lot of parents are a little bit receptive to any idea that is good for their kids. Be it their education, be it the food, be it whatever, you know, as long as the best is for their kids."

Two different types of cord blood storage are available in most countries including Singapore and Thailand: public cord blood banking and private cord blood banking. The umbilical cord blood of the newborn, which until recently was discarded at birth, can be donated to public cord blood banks for use by anyone in need. The umbilical cord blood units are held separately and registries are available for patients throughout the world. Although most countries have public banks, women do not routinely receive information about donation when they go for antenatal checkups. During my observations in public or, as they are called in Singapore, restructured hospitals, women in the late stage of their pregnancy are approached by the staff of the public bank and asked to donate. This is done discreetly whilst women, often accompanied by a family member, wait for their antenatal appointment. It often takes more than one session for women to agree to staff sitting down with them to explain what cord blood donation involves. However not all women are approached, due to limitations of time and sometimes a decision by a bank representative about whether or not the woman looks 'healthy' enough to donate.

Although public banks are increasingly available, donating umbilical cord blood is not always straightforward. Some national banks only accept blood from families from under-represented ethnic minorities or from families with a known genetic risk curable with blood transplant. This is done to capture as wide a sample as possible. In addition, not all hospitals or birth centers in a given country have the expertise to collect umbilical cord blood. Therefore, although a family may be willing to donate, the hospital may not be in a position to collect. In addition, confusion is common, especially regarding payments and benefits.

Private banks, of course, are more flexible; they collect in any hospitals or birth centers, and a representative is available at any time to collect blood after delivery. Private cord blood banking refers to

the collection of umbilical cord blood stored in private banks, or in storage space in public stem cell bank facilities, to families who wish to preserve the umbilical cord blood of their newborn. Private cord blood banking facilities have increased dramatically since 2000 with the emergence of regenerative medicine, whereby the potential of cord blood stem cells has gone beyond the use to substitute bone marrow in transplant and has expanded the potential therapy for a number of degenerative diseases in both adults and children.

Employees of private biobanks target women who present for antenatal checks at hospitals or clinics through promotional material and face-to-face conversations. Depending on the internal policy of the hospital and clinics, women and couples are approached on a regular basis and given information. Companies also reach their clients through marketing techniques, including social media campaigns, baby fairs, printed media, and television advertisements, depending on the context in which they operate. In Singapore, most biobanks sponsor prenatal talks with an array of neonatal experts, including doctors, breastfeeding consultants, and baby massage therapists, and run contests for parents with the possibility of a private consultation with the bank going on concurrently during the event. Once clients sign up, they are offered various payment plans, including a one-time fee that will cover payments until the baby is 21 years old, a 10-year plan with annual payments until the baby is aged 11 and then annual payments, and an initial fee with subsequent annual payments.

In Singapore, private banks offer deals to couples that sign up at any of the fairs or workshops and talks organized by them, with the initial payment at around SGD 1250 (c. US$1,000) and an annual fee of SGD 250 (US$200). There is the added advantage that families can pay for stem cell storage with the child development fund, an amount of money that the government gives to each child born in Singapore from Singaporean parents. With this incentive, the initial payment is reduced to SGD 625 and the difference is paid through the baby bonus. The annual payments remain the same. Once parents sign up, the mother is asked to have a blood test and to complete a form collecting demographic and health history information, and they are then given a cord blood collection kit to bring to the delivery.

Private banks are more aggressive in their campaigns than are public banks. Meiling told me she had just settled into her room at a private hospital and was getting ready to go into the operating theater to have a caesarian section for her twins, when the nurse who was helping her asked her if she wanted to buy additional benefits for her baby, including insurance for the ICU, baby photographs, baby hands and feet impressions, and stem cell collection.

> I think most mothers have heard of stem cell banking but they do not know so much until they get to the day of delivery. Because on the day of delivery and after the day of delivery, you will get like a few people visiting you trying to sell you things. I think the typical ones are if you want to have the feet or the hands, and then you will also be asked if you would like a photograph taken by a professional of the baby. And they were asking me for a photograph and the stem cells.

Meiling was very nervous and left it for her husband to decide whether they would sign on for the collection of umbilical cord blood or not. The nurse showed them two brochures, the husband chose one bank, and within a few minutes the representative of that bank was in their room. The process was quick: it only took a few minutes. Meiling told me that she bought the ICU insurance policy straight away, and that her husband bought the stem cell collection and storage with their baby bonus money.

In the context of stem cells, new meanings of kinship and social relationships emerge. For example, in an article in *The Straits Times* (5 May 2008), it was reported that a woman had stored the stem cells of her two children in 2005 and 2006, and although the youngest child had died after seven weeks due to a congenital heart defect, the mother had continued to store his cord blood. Stem cells are imbued with meaning beyond a common understanding such as medical insurance and regeneration, and bring new affections into play, new hopes, and the realization that a part of the child is still with the family (albeit in a laboratory). The lost child lives on in its stored blood.

What we are experiencing is the medicalization of kinship in which "family and kin relationships are being drawn into the biomedical domain" (Finkler 2000: 3), especially when related to the explanation of genetic transmission of diseases. Finkler's notions of kinship and transmissions are applicable to stem cells. Families decide to bank not only as an investment (whether they will use the stem cells or not) but also because there are perceived or real risks of recurrent diseases, often on

the basis of family history: "My husband and I both have a history of cancer on both sides of the family. We decided to bank our youngest's cord blood. Hopefully we will never need it" (FB message board on Viacord and Cryo-Cell group, 9 September 2009). Or as one woman I interviewed put it:

> Okay, I thought a little bit before I did it, I maybe was like when I was three to four months pregnant . . . after reading through it (some articles she was sent from friends), I decided to go for it. For two reasons actually, one is because of the child, in case they get, actually if they get sick and partly it is because of myself because my mum actually passed away from cancer. Her whole family actually died of cancer. So I have a very high risk of inheriting the genes.
>
> *(Nalina)*

These new forms of kinship may play a limited role in society, yet despite this, blood still has an important role in modern societies where biogenetic kinship is valued (Finkler 2000: 35).

Public and private stem cell banks have unique characteristics within tissue economies. Public banks create clinical value for cord blood by storing a wide range of tissue types from various ethnic groups. In contrast, because private banks store the stem cells into a private account, these cells are withdrawn from public market circulation. Tissues and body fragments have social lives. Umbilical cord blood has changed status in the last 10 years, from waste, regularly incinerated after birth, to a highly valuable therapeutic and remunerative material. However, in hospitals, waste tissue is used in two ways (Annas 1999: 1523). One is in medical research; the second is its use for commercial purpose. The waste or abandoned material is easy to use and is not subject to the ethical considerations tied up with informed consent procedures. The recent Human Tissue Act (2004) in Britain mentions that it is good practice but not mandatory to obtain consent for research on non-fetal products of conception (like the placenta or umbilical cord), and such types of tissue will continue to be used without consent requirements providing the proposed research using those tissues has ethics approval (Human Tissue Authority, Code of Practice, 2009, www.hta.gov.uk/guidance/codes_of_practice.cfm).

Given that, increasingly, diseases are given a genetic origin, it is not surprising that, reading various stem cell blogs on the Internet, parents decide to bank the umbilical cord blood when they have a family history of diseases such as cancer, Parkinson's, Alzheimer's, and so forth. Social groups form around a specific and shared characteristic of biomedical origin. These collective groups open new spaces for public debate using public spaces on the net. Community groups, NGOs, and individuals who want to bring clarifications, personal experiences, and advice in relation to banking stem cells have emerged as well. For example, the Parent's Guide to Cord Blood is a website set up by the parents of a girl who died of leukemia (http://parentsguidecordblood.org). The aim of the website and its work is "to educate parents with accurate and current information about cord blood medical research and cord blood storage options. . . . The second mission of the Parent's Guide to Cord Blood is to conduct and publish statistical analyses on medical research or policy developments which could expand the likelihood of cord blood usage."

Within the process of becoming parents and exploring the possibilities of using the umbilical cord blood, couples assign new meanings to blood whereby its biological, social, and even economic values cannot be separated but rather become connected and reconnected in the process of banking. With umbilical cord blood banking, decisions to donate or store stem cells with health implications for the family or the community are imbued with hopes for the future.

References

Annas, G. J. 1999 Waste and longing—The legal status of placental-blood banking. *New England Journal of Medicine* 340(19):1521–1524.

Brown, N., and A. Kraft 2006 Blood ties: Banking the stem cell promise. *Technology Analysis & Strategic Management* 18(3–4):313–327.

Finkler, K. 2000 *Experiencing the New Genetics: Family and Kinship on the Medical Frontier.* Philadelphia, PA: University of Pennsylvania Press.

Gunning, J. 2004 A worldwide study of umbilical cord blood banking. European Group on Ethics in Science and New Technologies. Opinion 19. Ethical aspects of umbilical cord blood banking. Luxembourg: Office for Official Publications of the European Communities.

Rucinski, D., R. Jones, B. Reyes, L. Tidwell, R. Phillips, and D. Delves 2010 Exploring opinions and beliefs about cord blood donation among Hispanic and non-Hispanic black women. *Transfusion* 50(5):1057–1063.

Genetic testing not only affects the individuals who receive reports on their genetic makeup. It also affects the siblings and children of the person who is identified as being susceptible to a specific disease. For example, when diagnosed with the BRCA gene, indicating a high risk of getting breast cancer and an elevated risk of other cancers, women have to decide who to tell and how. Like other stigmatized conditions, having the BRCA gene puts the individual into the position of revealing her diagnosis or not. Living with the social repercussions of the diagnosis may be very difficult, especially for people who have Ashkenazi Jewish heritage, among whom especially high rates of breast and ovarian cancer are due to this mutation. This risk profile is particularly disturbing where many people have lost friends and loved ones to cancers with these genetic origins, and where universal screening is encouraged, so pushing such women to take prophylactic action. While in the 1960s and 1970s, anthropologists emphasized that how people act is determined by culture, in the present genomic medicine has led to a renewed emphasis on heredity. Accordingly, anthropologists are studying how developments in the field of medical genomics lead to a rethinking of kinship. How does genomic medicine affect the way we think about family ties? Marilyn Strathern (1992) points out that the basic idea that offspring should resemble their parents, while they may also differ from them, has been extremely durable in Western culture, as evidenced in expressions like 'like father, like son.' How do people incorporate genetic test results into their discourses on family (non)resemblance?

The third case study, by Janice McLaughlin, shows how ideas about family resemblance play a role in consultations between parents of children with unexplained developmental abnormalities and pediatric geneticists, who nowadays can make use of 'whole genome sequencing' to find the genetic variations causing the disorder. She shows how clinicians adhere to a 'genotype first' process of diagnosis to identify unexplained developmental abnormalities. Although whole genome sequencing allows for complex biogenetic analysis of genetic variation, and defines relatedness at a molecular level, families continue to make their own assessments of similarity in everyday life. As an example, she describes how one grandfather saw nothing unusual about his grandson's height: "I just think it's the family," he remarked. "We're all tiny." McLaughlin shows how family members can use genetic test results to characterize and validate some relations as closer than others. People are surprised when, in some cases, genetic tests do not confirm the inheritance of a trait. The identification of a shared genetic disposition for learning difficulties, for example, creates a link between a mother and her daughter, as the mother finds parallels in her own childhood to the challenges faced by her daughter. McLaughlin suggests that the results of genetic technologies will not replace narratives of resemblance, but rather, will be incorporated into the social and intimate lives of families.

14.3 Genetics, Childhood Development and Kinship

Janice McLaughlin

Children with unexplained development problems and unusual (dysmorphic) characteristics are often referred to a genetic service or clinic to see if chromosomal variation may explain their issues. Patterns of referrals have increased in much of the global North as advances in genetic testing have expanded the genetic variations linked to a range of childhood conditions. Until now diagnosis has been a combination of family history, close examination of the child's features and biochemical analyses of the child's DNA from blood samples. Pediatric genetics is set to see significant changes in its diagnostic practices and possibilities over the next few years as we move into the era of whole genome sequencing (WGS).

Unlike current diagnostic practice, WGS, through complex biochemical manipulation of blood samples and bioinformatic analysis, enables (theoretically) all genetic variations within a person's genome to be identified. What in the Human Genome Project took billions of dollars and many years to do very soon could take thousands of dollars and days to produce. The most difficult element is the complex work required to separate out variations that are clinically meaningless from those that are significant. This is the key challenge (and current barrier) to bringing WGS into clinical practice. Considerable research activity is underway in multiple research studies across the globe to establish which variations that can now be 'seen' are clinically relevant. One such study in the field of childhood disorders is the UK Deciphering Developmental Disorders (DDD) study (http://www.ddduk.org/). The hope is that such studies will both explain the genetic underpinning of a range of developmental issues in children and have the potential to offer greater predictive power and therapeutic application.

While WGS remains primarily a research endeavor, elements of sequencing technology are entering clinical practice. For example, sequencing is being used to search for particular traits with already known clinical significance in areas such as immune disorders. These changes in clinical practice are already leading some commentators to suggest that in the future the child's body will become increasingly irrelevant to the diagnostic process. An editorial in 2008 in the *New England Journal of Medicine* proposed that "(c)linicians, like researchers, can now shift to a 'genotype first' model of diagnosis for children with unexplained developmental abnormalities" (Ledbetter 2008: 1729–1730). Medical sociologists and anthropologists have been quick to point out the dangers of a move away from an interest in symptoms displayed on the body to variations found in a computer simulation (Navon 2011). They warn of a future where variations found in DNA will be used to create "ontologically disputed borderline forms of disease" (Buchbinder and Timmermans 2011: 57).

Drawing from a study undertaken in pediatric genetics in the UK,[1] I explore the social and cultural significance of the body within childhood and kinship. Can the body be replaced by WGS findings in family practices of meaning making? And what happens when children help shape these processes?

Following the Body

The presence of the child's body during clinical consultations is significant to the implications genetics has to how the child is understood by family members (McLaughlin and Clavering 2012). However, if the detailed physical examination of the child's body becomes much less important in the future era of WGS, will that mean that the body will become less important to how the child is understood? In clinical observations parents were often impressed by the complex diagrams geneticists produced (all names given below are fictional):

Dad: It was fascinating 'cos you think, how can you do that with something, you know, that's so little? And just blast it apart.

(Brown Family, Second Interview with Mum and Dad)

Below, I suggest that lack of clinical interest in the body in WGS will not necessarily mean that the body will drift into the background and that biomedical processes will dominate. Assuming this will happen minimizes the social and cultural significance of how identities form for children via the important mediating influence of those close to them, particularly parents and other intimate family members. Exploring the significance of these broader processes of meaning making with and through bodies requires pulling back from the clinic to a broader landscape. While the clinic is a place of authority, it is not the only space within which children's bodies are represented, visualized, analyzed and made sense of. Multiple interactions can occur in multiple spaces, and the child's own enactment of her body may have a role in how others interpret it and give it meaning. One value of ethnography is that it allows the researcher to observe such interactions and to follow people through multiple places that play a part in forming their identity.

Resemblance

The way people in a family interpret a child is influenced by the way they look at and read their body, often in comparison to others, searching for resemblance. People trace resemblance and give

meaning to it through stories of similarities between family members. Existing familial understandings of shared inheritance may either support the possibility that a genetic variation of significance, or more commonly, that the factor in development, framed as a 'clue' to genetic peculiarity, was instead a shared family trait and appeared as perfectly normal to them. For example, a grandfather at a first consultation explained why he did not think there was anything significant or unusual about his grandson's height:

Geneticist to grandfather: And what about you?
Grandfather: No. I just think it's the family.
Geneticist: So, it's the family?
Grandfather: We're all tiny.
Geneticist: Hm. Let's just do the family tree.

(Dougherty Family, Observation of First Consultation, Mother, Maternal Grandfather, Son, Geneticist present)

Appeals to resemblance can also be used to emphasize connections and relatedness that genetics may not see or consider important. In one family in the study, the father's line was not reflected in the family tree the geneticist took in the consultation. The reason for the exclusion was that the trait being explored was only inherited via the maternal line. Biomedically, the father was irrelevant. However, the exclusion clearly pained him, as he felt he was being erased in some form as a component in the making of his daughter's life. In response he always spoke in interviews of ways she took after him both physically and in character:

Dad: She's got my temper!
Gran: Yes, I was going to say that.
Mum: Yes, yes.
Dad: Yeah, attitude and stubbornness.

(Henderson Family, Third Interview with Dad, Mum and Maternal Gran)

Through claiming resemblance, validated by the maternal side of the family agreeing, the father found a way back into accepted narratives that he is important in his child's present and future.

Another route to finding resemblance as meaningful is seeing it in others said to have similar variations in their genetic makeup. In the study, such resemblances were often found online as families searched for information about the types of variations or syndromes they had been told their child had. What they found were pictures of dysmorphology (unusual looking children). While one response was to express fear and discomfort that their child might be one of those children, another reaction was to find connection and community through interpretations of physical resemblance. At times, the virtual similarities found online and understandings of familial resemblance came together, reflecting ways in which bodily similarities were participating in practices of familial forms of recognition. The Todd/Richardson family were told on the phone that their child had a variation on a particular chromosome and were invited to a second consultation to discuss the finding. As with the others, they went on the Internet and saw pictures of children with the same chromosome error. They described what they saw as like "looking at their son."

Mum: We went through lots of websites, all about Chromosome X. We found a family down south. They have a four-year-old girl and we sent them a photo of Harry. We all agreed they looked exactly the same, only she had long hair. They have the same chubby cheeks and that look in their eyes.

We look across to Harry, who is playing with plastic shapes near the play house.

Mum: He does have slightly chubby cheeks but then, I think, he is only just over two years old, and his dad has quite a round face.

(Todd/Richardson Family, Observation Notes of Waiting for Second Consultation to Begin, Mum, Dad, Child present).

During the consultation the geneticist suggested that what they had seen on the Internet was not relevant as the variation was different from what they had understood from the telephone call. However, reflecting after the consultation, the father commented:

Dad: We could see how all these children look the same. Just having something different about your genes brings them all together, whatever the deletion-point-this-that-or-the-other is.

(Todd/Richardson Family, Observation Notes of Second Consultation)

Seeing resemblance is an important component to making connections with others, something the body is culturally positioned to provide.

Incorporating Genetics

It is more useful to think about the information and understandings that emerge from genetics as being incorporated into, rather than determining, kinship connections. One purpose of family stories is in shaping the boundaries of who is in and who is out. One maternal grandmother had a strong narrative that her family history was one of good moral character and physical health, passed on by the women in the family:

Gran: Very strong women in this family. When I think about every woman in this family, we're very strong women. You know I'm talking about like *my* blood line, my mam, grandmother, great gran, very strong women. Always been like that.

(Brown Family, Second Interview with Maternal Gran)

Her granddaughter was diagnosed with 'developmental delay' and was being seen by the genetics service. From early on, the grandmother had assumed the biological father must be the person she had inherited her problems from. Her justification was several examples of illness and learning disability found in his family and not in hers (she claimed). To her surprise, the genetics service said the genetic trait they had found came neither from the father nor mother (it was a de novo variation). Because genetics could not validate her separation between her family and that of the father's side, she switched her focus to emphasizing the inheritance of social and moral character rather than genetic matter:

Gran: So I bring this line up of going back. And you know, my granddaughter will say, "what about your mam? And her mam?" And I'll get pictures, and I'll say that was my mam, that's my nana. . . . And I say, look at her lovely hair, and she's got a lovely clean apron on, because obviously in them days they always wore the aprons. And I always seem to push, *clean* and *manners*. . . . They're not going to be, they're not going to be *dragged* up. . . . Because I was brought up, and so was my, this line, as you call it, these women behind me.

(Brown Family, Second Interview with Maternal Grandmother)

The grandmother moved between genetic and social versions of inheritance as she worked best to maintain a narrative that the family was of moral character, and some version of that inheritance would be passed on to her granddaughter.

The creative use of different versions of what families share, including genetics, was also evident in other families. Alice, who was nine years old, had been identified as having a genetic variation that the geneticists linked with learning difficulties. Her diagnosis also led to the identification of the same variation in her mum. In an observation and informal interview with Alice at her home, she commented:

Researcher: Did your mam say how you have the same as her?
Daughter: Yes.
Researcher: What do you think about that?
Daughter: Hm [long pause, looks up and smiles] Happy.
Researcher: Happy, in what way?
Daughter: We're the same.

(Collins Family, Notes of Single Interview with Daughter)

Likewise, the mother spoke positively about sharing this trait with her daughter—a connection she felt meant they were closer than she was to her biological son:

> *Mum:* Everything now is focused on looking ahead for Alice. Just having this information now for her will make a difference. . . . It helps make sense of things for me, just as it does for my mam, and my nanna, and my granddad. . . . All my focus is on both my kids. I'm really proud of them. I'm close to them both, but I'd say I have a special relationship with Alice. I think that's because I can see what she is going through. It is hard to think of the future for her. She is in mainstream school, the local school they both go to. There are great teachers there, really friendly, one lives just over the fields behind us. I went to a special school that was horrible, though they've changed now, but Alice is fine in mainstream. I don't see any problems for her with carrying on with that—she loves school.
>
> *(Collins Family, Single Interview with Mum)*

It is possible to read the mother and daughter's special connection as being made through the narrative of genetics. This would imply that genetics can be used to validate some relationships as being closer than others. However, this narrative is about more than genetics; it is important to read it within its full social history. The mother's childhood had been difficult, she had struggled in school and in social interactions, she had been bullied, marginalized and had terrible experiences of schools for 'retarded' children. The mother's story is of a shared connection to her daughter that is about being similarly different in body and mind (now with a genetic explanation), which will be lived (she hopes) in a very different way by her daughter, because she lives in a very different world than the one her mother grew up in.

Conclusion

WGS will produce new ways of capturing and analyzing genetic variation; however what will this mean to families, or indeed children themselves? Will complex algorithms and displays of biochemical analyses become dominant in interpreting children, particularly as "other"? For now I would say while this is possible, it appears unlikely. Children's bodies, in particular how they look, who they look like and who they don't look like, are integrated into the social and intimate lives of their families. The importance of embodiment, as practice and narrative, to kinship making means that it is unlikely to be simply replaced by other sources of narrative, instead it is more likely that WGS, like current genetic technologies and stories, will become part of how children's bodies are understood.

Acknowledgment

Funded by the Economic and Social Research Council, between 2008 and 2011, as part of a larger team, I undertook ethnographic research in the UK examining the experiences of children and their families who had been seen by a genetics service. The fieldwork, over an 18-month period with 26 families, consisted of a mix of non-participant clinical and non-clinical observations, narrative longitudinal interviews and creative practices (used with the children). Within families we worked with parents, siblings, other significant family members and the children referred (with the very young children that work was limited to the observations). Families also shared the material they were sent from the genetic service detailing what diagnosis (if any) had been made. The project obtained ethical approval through the NHS National Research Ethics Service (NRES).

Note

1. For a more detailed account of the research project I draw from here, see McLaughlin (2014).

References

Buchbinder, M., and S. Timmermans 2011 Medical technologies and the dream of the perfect newborn. *Medical Anthropology* 30(1):56–80.

Ledbetter, D.H. 2008 Cytogenetic technology—genotype and phenotype. *New England Journal of Medicine* 359(16):1728–1730.
McLaughlin, J. 2014 Digital imagery and child embodiment in paediatric genetics: Sources and relationships of meaning. *Sociology* 48(2):216–232.
McLaughlin, J., and E.K. Clavering 2012 Visualising difference, similarity and belonging in paediatric genetics. *Sociology of Health and Illness* 34(3):459–474.
Navon, D. 2011 Genomic designation: How genetics can delineate new, phenotypically diffuse medical categories. *Social Studies of Science* 41(2):203–226.

The Turn to Complexity

Two decades of mapping the human genome have led to the identification of 23,000 genes—which, it turns out, is equivalent to the number of genes found in a roundworm. Faced with these figures, observers have increasingly acknowledged that "nucleotide sequences themselves were neither the 'holy grail' nor the 'code of conduct' that the proponents of the projects hoped they would be" (Rabinow and Bennett 2012: 13). Clearly the identified genes could not account for the complexity of the human organism (Rheinberger 2004). Perhaps, as Evelyne Fox Keller (2001) argues, genes have outlived their role in understanding biological phenomena and heredity. It has become very difficult to define what genes actually do, and there is a substantial gap between the overflow of information and its "promised transformation into ameliorative and lucrative applications" (Rabinow and Bennett 2012: 14). As biologists continue to examine the complex regulatory systems through which organisms function, they realize that the phenomena they study are more complex than they imagined. In surveying this situation, Hans-Jorg Rheinberger (1997) argues that biologists need to build a middle ground between complexity and simplicity into their epistemic practices.

Such complexity is built into the framework of the field of environmental epigenetics, which examines the multiple, overlapping relationships between the environment and genes (Landecker and Panofsky 2013). In this subdiscipline, genes are not thought to determine behavior unilaterally, rather, diverse factors, such as violence, family life, and toxins, can affect our genetic makeup. In this context, the environment refers to both the physical and the social environment in which people live, and the uterine environment, which in turn is influenced by the external and internal (health and nutrition) environment of the mother. Using the notion of biological plasticity, researchers argue that biology and behavior are co-produced (Mol and Law 2007).

In the fourth case study in this chapter, Stephanie Lloyd presents the results of an ethnographic study conducted in an epigenetics laboratory where scientists have been exploring whether early childhood abuse is linked genetically to suicide later in life. More specifically, epigenetic researchers are examining how negative experiences in early life are embodied, physically changing genomic expressions and ultimately increasing people's chances of becoming, in her example, 'suicide completers.'

14.4 Suicide and the Epigenetic Turn

Stephanie Lloyd

Though elevated in particular eras, regions and subpopulations, suicide is an act deeply ingrained the past and present of human history. Those analyzing suicide from an anthropological perspective have described it as a type of sociality, a way of living as much as dying, intimately connected to time, place and people's personal lives (Staples and Widger 2012). Seen in this way, suicide has complex meanings and relationships with innumerable life factors related not only to people lost to suicide but also those around them.

The scope of suicide is now regularly documented alongside other 'health topics.' The WHO suggests that globally one person commits suicide every 40 seconds. Every three seconds someone

attempts suicide. Given these rates, suicide is of great concern as a clinical problem. Clinical researchers link suicide to developmental factors, pathological personality traits, psychopathology, and biological and genetic predispositions. They are most concerned with suicide attempters, as these people are statistically most likely to become what they refer to as 'suicide completers.'

My focus is on emerging epigenetic explanations of suicide that attempt to both overthrow and integrate the disparate lines of reasoning emerging from sociohistorical and clinical research. Epigenetic researchers suggest that negative early life experiences are literally embodied, physically changing individual genomic expression and ultimately increasing people's chances of becoming suicide completers. Though the science is in its infancy, the perspective is gaining currency and influence in mental health research and well beyond.

Environmental epigenetics is a subfield of epigenetics focused on how environmental factors—from socioeconomic disparities, to individual life experiences, to environmental toxins—affect the body. The rapidly evolving interdisciplinary field of research uses the notion of biological plasticity as a base upon which to construct theories of how nature and nurture co-produce biology and behavior. In a 2011 public lecture Michael Meaney, a leading environmental epigeneticist, identifies the foundations of contemporary environmental epigenetics in the work of biochemists over the past 10–15 years. This research, he contends, made it evident that "the activity of a gene depends upon the context in which it operates." Through the process of this research, he says:

> (I)t was found that some of those structural modifications that occur to the DNA [as a result of the environment] . . . they are not so dynamic, they can actually be long term. They can actually stably alter the structure of the DNA . . . we have all known that in the course of development or even in adult life, there are occasions when people are exposed to environmental events or to biochemical events that are so profound that they stably alter the activity of genes. In other words, the effect isn't simply there during the period of the event, it endures well beyond. . . .

This brings Meaney to observe that one can then ask how the social or educational environment, or nutrition in early life, could stably alter the genome. He compares the orientation of this research to studies of gene activity near the turn of the century. In that era, "everything seemed to start from the gene." Epigenetics research, he contends, displaces attention from the gene by underscoring the extent to which "the environment can influence the DNA which then influences particular traits." He concludes, "now the DNA . . . actually becomes integrated within the environment and we start to have a more complete understanding of how the environment literally produces biochemical structural changes to the DNA, that then produces changes in the phenotype [a behavioral or physical outcome]" (Meaney 2011).

Meaney provides a digestible, if widely encompassing, explanation of epigenetics and the critical role of the science in repositioning of our understandings of humans and how we become who we are at any given moment in our lives, from diseases to personality traits. However, the science he describes is an incredibly complex field, with competing theories and models muddled by difficulties in operationalizing the questions epigeneticists wish to pose in day-to-day lab work. For instance, how are environmental factors embodied and what is the impact of this embodiment?

A group of Montreal epigenetics researchers are trying to answer this question. Specifically, they ask, how do you look inside someone for evidence of early childhood abuse and then identify how this is linked to suicide later in life? Following Meaney's assertions about the epigenetic effects of early maternal care and documented links in psychiatric literature between early childhood abuse and later psychopathology and suicide, these researchers search for biological traces of abuse that occurred in childhood during what are referred to as 'critical moments' of neuroplasticity, when the brain is considered particularly sensitive to environmental factors.

Conducting this research entails many challenges. Epigenetic changes resulting from environmental exposure is dynamic, as Meaney noted. Further, they are tissue specific: if you want to know what the effects of abuse are on the brain, you need brain tissue. As a result, the Montreal researchers are dependent on their affiliated brain bank which houses thousands of brains, including those of suicide completers. In these brains, they search for epigenetic changes such as methylation patterns they consider to be the durable imprints of early childhood adversity. They then attempt to identify if these methylation patterns are distinctive from those in the brains of normal controls or even people lost to suicide with no history of child abuse. Thus, the work of these researchers focuses on the remains of suicide completers, samples of fixed or frozen brain tissues, in the hopes of identifying the particularities of the methylome that predisposes people to suicidal behavior.

In this case study, I focus on the incipient models that underlie and guide their brain-based research: models of how the environment—an event in the form of early childhood abuse—'gets into' people's brains and leads to a behavior—the enactment of suicide later in life. Constructing these models remains a distinct challenge. The lead scientist of the research team, Gustavo Turecki,[1] described how he conceived of the embodiment of adversity:

> We don't know how it gets in, we don't understand how it is that, let's say . . . a social event, whatever it is, or psychological event . . . gets into the actual genome. Basically we know associations. . . . So from the work in animals, that suggests a *causal* relationship between . . . events in the [early] life of the rats . . . or whatever model that's used: that negative environments induce epigenetic changes. So it's clear from the animal work that there's a causal relationship. Yet, even from the animal work, it's not clear how it gets to the genome. So how it gets from the actual experience to the genome, that is not clear. The hypothesis, primarily based on Michael's [Meaney] work. You know Michael's work is about tactile stimulation, so it's how the mom [rat] licks and grooms. . . . So it is really the stimulation of the skin that induces the changes. So in that case there are a few, let's say, putative mechanisms that are related . . . this tactile stimulation releases one neurotransmitter that then [affects] levels of one particular hormone, and that leads to a cascade of events that leads to these methylation changes. But it's not yet . . . 100 percent. It's not [yet] a robust hypothesis. . . . So that's what we know from the animal work, from the human we don't know anything. . . .

When I asked whether he believed a similar mechanism would nonetheless be implicated in humans, he replied:

> No, it wouldn't because it is a different mechanism . . . because in the rat . . . it is really related to the stimulation of the skin, which has nothing to do with the human experience, right? The human experience is more about psychological impact, so we still don't understand, that is a problem. We don't understand how is that emotions are processed let alone what the link is between emotions and the genome. So these are parts that have big question marks.

A geneticist (Carl Ernst) and postdoc (Paul) in Turecki's research group delved somewhat deeper into the challenge of ascertaining how an event is embodied:

Paul: It's a very large question and I guess every part of the neuroscience field is trying to understand this question using different techniques and tools. So we are using post-mortem brain tissues and we are making correlations, while people who are working with mice, for example, are trying to look more closely at causality, but then it is only a model [of mice, with unknown implications for humans], so every approach has its limitations . . . if you wanted to speak more precisely about child abuse, I mean, I guess there are many systems in the brain that are dedicated to the neuronal coding of life experiences and its different components, so there are cognitive components, there are emotional components, there are memory components, and so every component is going to be modified and impacted by life experiences.

When I asked how they saw the neuronal coding leading to durable changes, Paul responded:

Paul: So then it's a very long chain of events . . . you could imagine that some brain regions are encoding the emotional aspect of pain, okay? And so when you are subjected to repeated child abuse these regions are repeatedly activated, and so this triggers repeated release of some neuropeptides, and some neurotransmitters in this specific region are going to trigger specific downstream signalling pathways that are going to be modified in the long term and this may be long-lasting . . . up until adulthood. I compared [the abused research subjects, i.e., suicide completers] to subjects who were not exposed to child abuse and this, this [difference] . . . is reflected at the epigenomic level.

In terms of how they conceive of the 'signal' ultimately leading to the changes at the epigenetic level, they contend:

Carl: Well, they could be linked, I mean . . . I wouldn't phrase this just in term of methylation, but just like dynamic changes to the genome, to modulate gene expression and the protein translation, it is all that. But that's a good example, you have some neuronal network that's responsible for coding, pain, it releases some . . . [Paul continues.]

Paul: Or reward, or I mean . . . emotions, memory, because you have to remember the adverse experience, you have to, I mean, to develop strategies to avoid them, so there is a cognitive part because you are trying to implement behavioral strategies to avoid your mother when you are feeling that she is becoming aggressive, I mean, there are so many components, it's amazingly complex, right?

Carl: I agree with all that, but then you have the release of, let's say, some peptide, it binds to its receptor on the outside of the cell, that triggers the second messenger system in the cell, which ends up interacting with the genome. This is factual, this happens all the time, it happens with a lot of peptides we know about. Some of those genomic changes may inform [its] DNA methylation state, and if that neuronal network is repeatedly activated by a constant stimuli, in this case abuse to the child, the constant release of that hormone, let's just say, or peptide or whatever, the constant stimulation in that second messenger pathway, and the constant interaction of the genome with the molecular factors end up having a long-lasting change, which could be DNA methylation, which could be histone changes [another epigenetic mechanism], but just global change in the genome, that are gonna result in up, down, changed regulation. I mean, these things *do* happen, if you eat broccoli every day for a year, you are gonna change the epigenetic pattern of your stomach cells, y'know, you are gonna change the bacteria in your gut, you know, there's tons of stuff that happens because of some external stimulus. We're just using a complicated one, like a behavior, like child abuse . . . but if you just change your diet, your epigenetic pattern is gonna change in your food related cells.

Carl's statement gets at the heart of the challenge in their work: trying to link a complex life event (early childhood abuse) to what they see as a pathological behavior (suicide) later in life. Social and personal environmental factors such as child abuse are complex and their putative effects are not as easily traced as compared to relatively more straightforward environmental factors such as toxins, whose effects are nonetheless complex. Trying to link biological changes to suicide later in life represents an additional challenge, as it is not a well-defined disease state, but a complex behavior.

Added to this uncertainty of how to link an event to a behavior at a biological level, there are questions about the fidelity of the epigenetic traces they seek to characterize, given that their research methods involve looking for relatively distant history imprinted on the brain. When asked how he knows with any certainty that he is seeing embodied childhood abuse in the brain, Turecki responded:

> We don't. This is a *clear* problem of the approach that we have. So ideally what you would like is, you know, to have access to the brain before it [abuse] happens and after it happens, and then look at the consequences. But you cannot. So, in humans, because what we study has to be based on the study of the brains, you can only have access to the brain after people die. So any other ways of looking at the brain would be limited. So these individuals were abused, a lot of things happened after they were abused in childhood, and they died many years later. We don't know if what we are looking at is directly related to the abuse or as a consequence of everything that happened after, or a combination of both. We don't know.

Their beliefs about plasticity, induced durable changes in the brain and how this leads to behavior are constantly shifting as new findings are produced. Each piece of research provides footholds for them to move forward, with a plethora of new questions.

Correlating a methylation pattern with a behavior is at least as difficult as tracking its embodiment, as Turecki notes:

> Every time we find a methylation pattern, so the first question we always ask is: what is its functional implication? Does . . . differential methylation in this area, does it lead to different function somewhere or not? . . . But we don't [yet] understand the function implication of these genes [where differential methylation patterns are identified]. . . . So, then what you can do? So there is this one study that we are doing. . . . [linking differential methylation to regulatory outcomes on a specific gene] So this is a big story that took a lot of work . . . then after all this work, we injected viruses containing the [genetic] sequence that we wanted to test in the brain of mice. . . . And when we do that we induce the expression of this thing, the mice become more aggressive, significantly more aggressive. So that is the way you can follow up [on] . . . the *behavioral* consequences of this differential methylation that you find.

By complementing human studies with animal models, they are able to begin painting a portrait of the process whereby early childhood abuse is linked to a methylation change and a behavior, in this case aggression, a trait associated with suicide. Gustavo considers this a considerable success.

Carl remains less certain about the solidity of behavioral epigenetic theories in general:

> You know what I want? I want one example of a behavior . . . I don't care what it's in. Where some event, some stimulus is given to the animal and you can repeatedly see an obvious, clear, clean epigenetic mark . . . I just want . . . some external environmental factor that is actually causing some molecular epigenetic change. That's all I want . . . just *something*, and I've yet to see anything that shows a causal link [to his satisfaction] between an outside behavior and DNA methylation, or whatever, pattern. . . . I just think, we just need a *model*. If it's true [that child abuse can lead to methylation that is still visible in the brains of suicide completers] then we should be able to find it. . . .

Given their professed uncertainty and the challenges inherent in their research, one might be tempted to ask why they bother asking such questions. Doubt that plagues their nascent theories notwithstanding, Carl noted that they *do* know that experience affects biology and these findings are enough to push them to continue looking for causal evidence of their hypotheses. As they search for this proof, they focus on mapping as robustly as possible the molecular traces of abuse they are able to render visible in the brain by virtue of their lab work, moving forward pragmatically and casting aside their doubt and uncertainty in their day-to-day practices.

Their molecularized view of suicide risk, in which the risk profile of individuals who die by suicide is constructed in their absence through epigenetic research on their remains, results in the origin of suicide risk and ultimate suicidal behavior being shorn of its links to proximate factors such as pain, personal loss or even imitation, and equally, of other environmental circumstances whereby suicide might be seen as an act of defiance against a political system or state of injustice. Instead, the time frame of interest is shifted to distal factors earlier in life, such as abuse suffered during childhood at critical moments of neural plasticity. The induced risk profile in the brain is ultimately seen as leading to suicide completion. Simultaneously, diagnostic attention and early therapeutic intervention shift temporally leading to earlier clinical surveillance and enrollment in risk management. Epigenetic research is lending support to molecular characterizations of mental illness characterization overall.

The epigenetic view of suicide risk follows on other epigenetic research in which the environment is increasingly viewed as a set of molecularized risk factors to approach with trepidation, with limited attention to molecular 'protective factors.' This research has profound implications beyond mental illness including understandings of humans as 'biosocial becomings' (Ingold and Palsson 2013: 9). In this view, humans are constantly in formation with biological and social forces interacting fluidly. While the researchers cited in this text adopt something similar to this biosocial view of suicide and human development, the difficulty of operationalizing complex biosocial developmental pathways evidently remains a significant challenge. As a result, complex fluidity becomes stunted, as researchers reductively focus on the few risk factors their current tools and practices can identify and measure, diminishing the complexity of experience and behavior in the process.

Note

1. Principal investigators of the team have waived anonymity as the distinctiveness of their research makes them readily identifiable. Trainees and staff in the research team have been anonymized.

References

Ingold, T., and G. Palsson 2013 *Biosocial Becomings: Integrating Social and Biological Anthropology*. Cambridge, UK: Cambridge University Press.

Meaney, M. 2011 Panel member in Beyond your genes: Epigenetics, and how early experiences may affect your health later in life. November 30, McCord Museum, McGill University, Montreal, Canada. http://publications.mcgill.ca/medenews/2011/10/03/beyond-your-genes-epigenetics-and-how-early-experiences-may-affect-your-health-later-in-life/

Staples, J., and T. Widger 2012 Situating suicide as an anthropological problem: Ethnographic approaches to understanding self-harm and self-inflicted death. *Culture Medicine and Psychiatry* 36(2):183–203.

Because the genes unraveled in the human genome project have failed to provide clear-cut codes to many of the biological processes in our bodies, and because biological processes are the result of complex interactions between environment, genetic makeup, and lifestyle, it has proven much more difficult than expected to develop preventive and curative interventions based on the results of the human genome project alone.

Synthetic Biology

In the new millennium, synthetic biology has emerged as a new field of research in which new therapeutics are being developed. Synthetic biologists aim to construct completely novel biological entities and redesign already existing ones, and to re-engineer complex biological systems and make targeted interventions possible. They have succeeded in making synthetic insulin from the bacterium *Escherichia coli,* are developing a precursor to the antimalarial artemisinin from *E. coli* and yeast, and are developing a semisynthetic derivative of artemisinin to enhance its bioavailability. They have also created more precise ways of diagnosing disease, based on people's specific genetic makeup, allowing for more targeted therapeutic interventions.

Calvert (2010: 97) suggests that synthetic biology aspires to "draw inspiration from the technological achievements of other branches of engineering, such as aircraft and computers, and conclude that it is 'economically and socially important that we improve the efficiency, reliability and predictability of our biological designs' (Arkin 2008: 774);" synthetic biologists aspire to replicate the successes of engineering. This cutting-edge science, however, is surrounded by a great deal of uncertainty. What kinds of 'interventions' will be possible? What are the risks? What are the ethical questions related to engineering biology?

The fifth and final case study in this chapter is concerned with the way in which people in the United States and the United Kingdom view the benefits, risks, and possible future applications of bio-engineered products, including cognitive/memory enhancements via chips implanted in the brain, and newer, stronger, lighter-weight and longer-lasting prostheses. These innovations both involve nanotechnologies—tiny engineered particles and structures that range in size from 1 to 100 nanometers (one nanometer is one-billionth of one meter). Synthetic biologists are especially interested in nano-enabled drug-delivery systems. The small size of the particles makes it possible to better target delivery, including across the blood-brain barrier. Worldwide, nanotechology development is the focus of significant public and private investment, and nanotechnology is being used in pharmaceuticals, diagnostics, tissue regeneration, and cancer treatment, offering glimpses of bionic/cyborg futures.

14.5 Techno-Benefits and Social Risks

Barbara Herr Harthorn

US and UK publics hold diverse, complex, and often conflicted views as they co-imagine and debate potential futures for medical and enhancement nanotechnologies in deliberative workshops. In contrast to fears their governments express about potential public backlash spilling over from past concerns about genetically engineered organisms, food, and other new technologies, both US and UK publics overwhelmingly considered a future embellished by new nanoscale medical technologies to be beneficial, demonstrating a surprisingly pro-technology acceptance of these largely unknown technologies, including those with radically new and different properties, functionalities, and capacities (Pidgeon et al. 2009). People did raise significant concerns, however, related to the unlikelihood of equitable distribution of these goods, and the trustworthy management and wise governance of their safety and potential unintended consequences by corporations and governments.

Nanotechnologies are a large class of engineered particles and structures ranging in size from 1–100 nanometers, where 1 nanometer measures 1 billionth of a meter, with exciting new optical, chemical, and electrical properties at this molecular scale. Scientists and engineers synthesize these nanoscale particles and devices from an array of materials, some of which, like carbon nanotubes, have no corresponding forms at larger scale. In the US and now over 40 other countries around the globe, nanotech development has been a focus of significant public and private investment; in the US, public investment takes place through the National Nanotechnology Initiative (NNI), founded in 2000 (see nano.gov). Nanomaterials are currently being incorporated into an ever-increasing range of products and devices, including an estimated 247 nanomedicine applications as of late 2013 (Etheridge et al. 2013). Yet despite approximately $20 billion investment in US R&D so far, public awareness of nanotechnologies is low (see Satterfield et al. 2009).

How we form trajectories for the future is a critical one in anthropology broadly and in studies of public imaginaries about techno-medical futures specifically. Since Margaret Mead's anticipatory anthropology, anthropologists have asked probing questions about how people make sense of the future across cultural and other boundaries, and how new technologies foster fundamental changes in contemporary culture and society. Cultural and social landscapes of inequality play an important role in such processes, and ideas about risk and the ethnography of contemporary fractured, ruptured experience are a notable part of this story.

The Nanomedicine Case

Nanotechnologies are being developed for use in products such as pharmaceuticals, medical imaging and diagnosis, implantable materials, tissue regeneration, multi-functional systems that incorporate several such capabilities, and especially cancer treatment (Etheridge et al. 2013). The promise of targeted drug delivery at the molecular site of incipient tumors offers therapeutic drug delivery, but far more potentially 'transformative' (and disruptive) futures are anticipated with the introduction of these technologies into personalized medicine and point-of-care diagnostics. For example, biomarkers of a huge array of diseases will be instantly discernable by 'lab on a chip' or 'lab on a pill' devices much as home pregnancy tests and implanted diabetes insulin pumps currently provide local diagnostics and treatment. The unusually strong and lightweight characteristics of nanoenabled materials make them attractive for prostheses, and when combined with nano tissue regeneration, offer glimpses of imminent bionic/cyborg futures.

In 2007 in the US and UK, and again in the US in 2009, my colleagues and I convened a number of small quasi-representative groups of everyday citizens to engage in extended (4.5 hours) facilitated dialogue about the benefits, risks, and imagined future implications of these novel medical technologies. Groups ranged in size from 9–15 participants. We selected across what were then judged to be near-, middle-, and long-term technologies as the main nanomedical topics for discussion: lab on a chip (remote, low cost, low energy, rapid diagnostics at point of care); lab on a pill (multi-function molecular device with capacity to travel undetected within the body to the site of tumors which it can then diagnose and treat in situ with 'nano bombs'); new, stronger, lighter-weight, longer-lasting prostheses (e.g. for hip and other joint replacements); and, the idea of cognitive/memory enhancement via implanted chips in the brain.

In general, people were deeply ambivalent. They had gained sufficient knowledge about these esoteric technologies to enter into informed, reasoned, and in some cases passionate debate about the benefits and risks they potentially posed to individuals and society (Pidgeon et al. 2009). Medical technologies, in comparison with energy technologies, produced a far more individualized response, and risk concerns centered primarily not on the technical risks posed by uncertainties about physical/technical hazards of new materials, but on social risks or societal hazards—particularly the potential for inequitable distribution of both benefits and harms, for invasion of privacy, for loss of care through remote sensing, self-management systems, and for irresponsible or incompetent governance of what many saw as unruly and greedy corporations. Most participants also drew quite sharp distinctions between technologies for restoring 'normal' functioning and those that might enhance abilities beyond the normal, although a minority of participants fully embraced more extreme aspects of potential bodily and cognitive enhancements and, thus, the end of death as we know it.

Targeted Drug Delivery

The cancer context is, unsurprisingly, one with which many participants had had some direct or indirect experience, and perceived urgency for new, more effective and less debilitating treatments tended to reduce perceived risk. For example, in a nanomedicine session in the US in 2009, participants readily agreed that using a risky application to save someone's life was an entirely different thing from using it in 'a cosmetic' or 'another salt shaker.' The touted benefits of earlier tumor detection and molecular-level treatment as a future replacement for full-body chemotherapy and radiation were intuitively appealing to most participants:

> As a healthy individual I think I would be leery of it at first but I know people that have cancer right now and I know that they are just fighting for survival and that their views might be a lot different than mine. They might not worry so much about it because they are not healthy.
>
> *(Jacquelyn)*

Yet technology also evoked many concerns. Some related to the specifics of how this embodied technology would work. For example, issues of controllability focused in particular on information and privacy, including how imperfect or intercepted transmission of information from mobile-embodied devices to medical practitioners could result in loss of privacy (and potentially, loss of rights to medical insurance if the information disclosed a disease):

> I would be okay with the information being used you know on like a general level but if it is used as a specific way to you know discriminate against someone you know with employment or something like that, that is definitely something that is very troubling.
>
> *(Ross)*

> There is one thing I was thinking about, the way we sort of tested Internet technology was to put it out there, and then also when we discovered we had spam, and then we built spam filters. But, I don't know that I, if I had a lab on a pill, I don't know that I would want to use that as a test, figure out how people are gonna hack into that, and then you know, I mean if it's transmitting it could be receiving, it's kind of an interesting thing.
>
> *(Jordan)*

> I think that that [technological controls] is essential, that yeah, because these devices are invisible it is something that the individual it comes prepackaged you cannot manipulate, it is not like a radio that you can turn it on and off. Be willing to develop devices that individuals will have to block information to see if maybe the particular pill is not genuine or . . .
>
> *(Simone)*

Remote sensors, which are likely to become widely used applications of nanotechnologies and include those in lab on a pill/targeted drug delivery, raised heartfelt issues about self-management of care and technological (robotic) substitution for direct, human, hands-on care. Other concerns centered on more general social hazards and suggested underlying ambivalences about the desirability of advancing technological solutions to societal problems in the face of many apparent contradictions posed by increasing inequalities, perceived loss of care, dehumanizing practices, and human foibles and weakness. Trust was a main issue and included questions of trust in technological R&D as well as in medical professionals' knowledge and dissemination. Also, many people questioned whether the new technology was really needed and whether it really would do more than current technology, whether technological fixes could really solve problems, and how cost entered into it. People often wanted the technology but resented the ever-escalating costs associated with this:

> I glanced at this one here [an article] and the thing that really bothered me and I think the whole thing is, it's from the concept of profit. Do we need cosmetics or personal care things which are going too expensive now, more than what, you know, what they really are. To put nano materials in that to further enhance it at double the price now where it leaves. *It's where you use it for making the most money rather than for doing the most good*.
>
> *(Gary)*

> I want to discuss the fact that what we are doing is, we are really looking at the end result and not the cause and that what we are doing is fixing something but without saying why. And I think that there's moral implications with saying why do we need all of these things? If we have bad water or we have pollutants, putting that little pill in or a microchip will get you an end result, but we are still not dealing with the fact that we have these pollutants, that we have issues that we are simply skating over and I think there are areas that still need to be looked at. . . .
>
> *(Melanie)*

In comparative discussions in the US and UK, another difference that emerged was that US participants more consistently adopted a consumerist stance to discuss the meanings of nanomedical technologies. They tended to understand the technology as a commodity, as 'goods' to be acquired, and that stance drove a sense of desirability, of consumer choice as the same thing as personal choice, and of competition for desirable resources. US participants seemed to impute perceived benefit more uncritically than those from the UK, who had a deeper understanding of risk controversies and deliberation as outcomes of past governmental risk management mistakes.

One aspect of this consumerist stance included a 'trickle down' idea about benefit distribution among US but not UK participants—they thought that access would be restricted to the wealthy initially, but would eventually become more universally affordable and available. In the UK, the benefits were seen as remaining with industry and the wealthy.

> These developments will be expensive, that means they could very well be limited only to the monied classes and they won't be available throughout society or the world.
>
> *(Sadie)*

> I think in that sense it might be in a lifetime or two but in the future it's like vaccines, like getting a flu shot. It will be available for future generations, but we have to start somewhere.
>
> *(India)*

Concerns about over-reliance on technology and laziness were recurrent throughout the discussions, and reflected deeper moral issues about the seductions of technologies and human susceptibility to poor choice making when presented with such easy (but costly) options.

> You know, *it's just a quick fix*. You know, instead of me, . . . right now my girlfriend said I'm a little fat, so I could get a pill, a fat burner pill, but I'm riding my bike to work every day and I'm losing weight so it's, you know, what we always want—that pill—we always want to give me something to fix so that I can continue my unhealthiness.
>
> *(Tate)*

Intelligence Enhancement

US President Bill Clinton introduced the National Nanotechnology Initiative in 2000, when he conveyed the excitement of this nanotechnology 'revolution' by inviting us to "(j)ust imagine . . . shrinking all the information at the Library of Congress into a device the size of a sugar cube" (http://www.nature.com/news/2010/100901/full/467018a.html). In exploring possible future uses of nanotechnologies to enhance intelligence and memory, discussion splintered between imagined enhancement of intellectual capacities in general or to increase specific knowledge. Participants were concerned about what was 'natural' in enhancement technologies, but also what was necessary or unnecessary, and how enhancement could unfairly give advantage to some more than others.

> I think that living forever, it's—I don't think it should, we would become very overpopulated. . . . So we live forever, when people come and then when people born and then it gets more populated and more populated and we just keep living forever. And I think that, I mean it's good to have it, in the sense that it helps you with, you know, give strength. That's good, but to be able to use over- over strength yourself, that's just wrong because you're pretty much, if you want to become a basketball player like he said or baseball player you could, you could become

> maybe because of the little nanos that make you stronger, and so people that don't have it, that are trying their best to do it, that's kind of wrong.
>
> *(Yolanda)*

Discussions readily moved in the direction of seeing the potential for increasing inequality through unfair access and possible misuse, while discussions about enhancement versus therapy repeatedly raised issues about whether or not living longer was a social good.

> There's moral questions throughout . . . this whole idea is, is ethically a mine field isn't it, for every facet of it. You know will it be like the reparative medical stuff, the enhancement stuff, the fact that if it could be used for this good it can be used to making people clever, it can made, used for making dumb; if it could be used for making people superpowerful, it would be able to make people, you know, fall apart at the seams, and you can't see it, you know. So it's the sort of base terror, isn't it, you're being haunted by something you don't actually know you're being haunted by, because you can't see it, you can't feel it unless you've got those crystals somewhere embedded in your arm or something.
>
> *(Lance)*

The speed of technological change also seemed to challenge "our ethical foundation," as Sam described it: "I'm not sure we have the luxury of time, nanotechnology is changing so fast, the capabilities are increasing so rapidly, that maybe our ethical foundation isn't sufficiently developed to observe, analyze, and make recommendations, on what's happening" (US 2007, male).

Conclusion

Public narratives about nanomedicines that emerge in deliberative dialogue reflect a distinctly postmodern and fractured set of ambivalences about risk, benefit, and inequality; distributive justice, technological desires, deep distrust of government and/or corporate actors; and uncertainty about public preparedness for full participation in the emergent international project of 'responsible development.' In this description of a series of discussions with diverse groups, social location and identity played a major role as participants debated and staked out positions on the multiple meanings of health and harm, risks and benefits, and the deeper ethical challenges posed by new technologies for therapy and human enhancement. As illustrated in other anthropological work, medical technologies are not stand-alone 'objects' bearing only technical attributes, as often conceptualized and described in the science and engineering world, but rather are inextricably bound to and entangled with the social worlds that they inhabit and through which they are constructed.

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References

Etheridge, M.L., S.A. Campbell, A.G. Erdman, C.L. Haynes, S.M. Wolf, and J. McCullough 2013 The big picture of nanomedicine: The state of investigational and approved nanomedicine products. *Nanomedicine: Nanotechnology, Biology, & Medicine* (9):1–14. Accessed from http://dx.doi.org/10.1016/j.nano.2012.05.013

Harthorn, B., C. Shearer, and J. Rogers 2011 Exploring ambivalence: Techno-enthusiasm and scepticism in US nanotech deliberations. In *Quantum Engagements: Social Reflections of Nanoscience and Emerging Technologies.*

T. Zulsdorf, C. Coenen, A. Ferrari, U. Fiedeler, C. Milburn, and M. Wienroth, eds. Pp. 75–89. Heidelberg, Germany: IOS/AKA Press.

Pidgeon, N., B. Harthorn, K. Bryant, and T. Rogers-Hayden 2009 Deliberating the risks of nanotechnologies for energy and health applications in the United States and United Kingdom. *Nature Nanotechnology* 4(2):95–98.

Satterfield, T., M. Kandlikar, C. Beaudrie, J. Conti, and B.H. Harthorn 2009 Anticipating the perceived risk of nanotechnologies. *Nature Nanotechnology* 4:752–758.

Interest in the cyborg in anthropology emerged in the 1990s, in response to developments in the field of assisted reproduction, including techniques such as in-vitro fertilization. Robbie Davis-Floyd and Joseph Dumit (1998), and the authors who contributed to their edited volume, point to the utility of an ethnographic inquiry that does not reject technologically assisted reproduction as unnatural. Instead, they argue, ethnographers should use the metaphor of the cyborg to better understand how reproduction is mediated by different kinds of technoscientific interventions, and the implications of this in terms of biological, cultural, and psychological evolution. More recently, Lenore Manderson (2011: 63) has observed that with the rapid development of bio-engineered options, cyborg bodies have become increasingly ordinary, even expected, just another item on a menu of medical interventions for people seeking treatment or repair.

In this chapter, we have illustrated how developments in the field of genomic medicine and synthetic biology are rapidly changing how we understand our bodies, as well as what we expect from physicians and surgeons, their procedures, and medications. We are offered many techniques through which we can manage our lives, including rapid diagnostic tests that tell us our genetic makeup and that allow for more targeted and tailored therapies. Our cyborg bodies are increasingly commonplace. While geneticists were initially optimistic about finding the biological basis of life, today, however, they acknowledge that much of life is not explained by genetic sequences. Both our genetic makeup and our risk of disease are affected by the circumstances in which we live our lives, and gene expressions are mediated by environment and lifestyle, pointing the direction for new medical research. In personalized medicine, information on our genetic makeup is combined with other biomarkers, bodily traits, and 'lifestyle' data, and combined with up-to-date data on therapeutic efficacies to make treatment decisions. Such advances open up as many social and ethical questions as they resolve biomedical ones, creating a new demand and urgency for medical anthropological research.

References

American Academy of Pediatrics Section on Hematology/Oncology, B.H. Lubin and W.T. Shearer 2007 Cord blood banking for potential future transplantation. *Pediatrics* 119(1):165–170.

Arkin, Adam 2008 Setting the standard in synthetic biology. *Nature Biotechnology* 26(7):771–774.

Bateson, W. 1906 The progress of genetic research. Third Conference of Hybridization and Plantbreeding, London: 90–97.

Calvert, Jane 2010 Synthetic biology: Constructing nature. *Sociological Review* 58(Supp.):95–112.

Davis-Floyd, Robbie, and Joseph Dumit, eds. 1998 *Cyborg Babies: From Techno-sex to Techno-tots*. New York: Routledge.

Flaherty, Devin, H. Mabel Preloran, and Carole H. Browner 2014 Is It 'Disclosure'? Rethinking tellings of genetic diagnosis. In *Disclosure in Health and Illness*. M. Davis and L. Manderson, eds. Pp. 89–103. London: Routledge.

Happe, Kelly E. 2013 *The Material Gene: Gender, Race, and Heredity after the Human Genome Project*. New York: New York University Press.

Johanssen, W. 1909 *Elemente der Exakten Erblichkeitslehre*. Jena, Germany: Gustav Fischer.

Keller, Evelyn Fox 2001 *The Century of the Gene.* Cambridge, MA: Harvard University Press.

——— 2003 *Making Sense of Life: Explaining Biological Development with Models, Metaphors and Machines.* Cambridge, MA: Harvard University Press.

Klawiter, Maren 2008 *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism.* Minneapolis, MN: University of Minnesota Press.

Landecker, Hannah, and Aaron Panofsky 2013 From social structure to gene regulation, and back: A critical introduction to environmental epigenetics for sociology. *Annual Review of Sociology* 39:333–357.

Lock, Margaret 2013 *The Alzheimer Conundrum: Entanglements of Dementia and Aging.* Princeton, NJ: Princeton University Press.

Manderson, Lenore 2011 *Surface Tensions: Surgery, Bodily Boundaries, and the Social Self.* Walnut Creek, CA: Left Coast Press.

Meaney, M. 2011 Environmental epigenetics: How childhood experience regulates your genes. Lecture, Center for Studies and Behavioural Neurobiology, Concordia University, Montreal, Canada.

Mol, Annemarie, and John Law 2007 Embodied action, enacted bodies: The example of hypoglycaemia. In *Biomedicine as Culture: Instrumental Practices, Technoscientific Knowledge, and New Modes of Life.* Regula Valérie Burri and Joseph Dumit, eds. Pp. 87–107. London: Routledge.

Olby, Robert Cecil 1974 *The Path to the Double Helix: The Discovery of DNA.* Seattle, WA: University of Washington Press.

Petrini, Carlo 2014 Umbilical cord blood banking: From personal donation to international public registries to global bioeconomy. *Journal of Blood Medicine* 5:87–97.

Rabinow, Paul 1996 Artificiality and enlightenment: From sociobiology to biosociality. *Essays on the Anthropology of Reason.* Pp. 91–111. Princeton, NJ: Princeton University Press.

Rabinow, Paul, and Gaymon Bennett 2012 *Designing Human Practices: An Experiment with Synthetic Biology.* Chicago, IL: University of Chicago Press.

Rapp, Rayna 2000 *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America.* New York: Routledge.

Rheinberger, Hans-Jörg 1997 Experimental complexity in biology: Some epistemological and historical remarks. *Philosophy of Science* 64(Supp.):S245–S254.

——— 2004 Introduction. In *Classical Genetic Research and Its Legacy: The Mapping Cultures of Twentieth-century Genetics.* Hans-Jörg Rheinberger and Jean-Paul Gaudilliere, eds. Pp. 1–5. New York: Routledge.

Rose, Nikolas, and Carlos Novas 2005 Biological citizenship. In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems.* Aihwa Ong and Stephen J. Collier, eds. Pp. 439–463. Malden, MA: Blackwell.

Strathern, Marilyn 1992 *After Nature: English Kinship in the Late Twentieth Century.* Cambridge, UK: Cambridge University Press.

Venter, J. Craig 2007 *A Life Decoded: My Genome, My Life.* London: Penguin.